

Quality Care: The Perspectives of Frail Elderly

Completed in 1996, this narrative was an introductory report to the Partnership Program based on interviews with elderly consumers in Wisconsin. Subjects included individuals enrolled in the Program for All-inclusive Care for the Elderly (PACE) and the Partnership Program at ElderCare of Dane County.

Barbara Bowers, RN, Ph.D.
University of Wisconsin-Madison
School of Nursing

Sarah Esmond, BA
University of Wisconsin-Madison
School of Nursing

Elizabeth Holloway, Ph.D.
University of Wisconsin-Madison
School of Education

Sally Norton, RN, Ph.D. (c)
University of Wisconsin-Madison
School of Nursing

**For more information about this report or the Quality Research, please call:
608-263-5299**

Introduction

The thirty-one elderly consumers interviewed for this study consistently evaluated quality of care by the quality of their relationships with providers. In most instances, satisfaction with the interactional component of the relationship was tantamount to satisfaction with the care. Numerous examples of both high and low quality care were consistently defined by the quality of the interactions and the relationship between the consumer and the provider rather than by the clinical outcomes. The relationship with a provider was not and could not be separated out from the quality of either the processes or outcomes of care delivery.

Patient Satisfaction Tools

In general, patient surveys and professional assessments consider competence of the provider, appropriateness of the services, and nature of the outcomes apart from the quality of the personal interactions between patients and their families. These items are evaluated separately most of the time.

Most of the elderly subjects interviewed for this study had never completed a patient satisfaction survey. The few who had done so had clearly based most, if not all, of their responses on their feelings about the primary provider and their relationship with that person. Their responses, regardless of area addressed, were influenced significantly by that primary relationship. Several of the consumers also indicated that they would be unwilling to fill out such a survey, especially if they were unsatisfied with some aspect of the service encounter. This raises serious questions about patient satisfaction surveys that often ask patients to distinguish between the quality of the care and the quality of the interactions. The reluctance to provide

negative feedback, especially when the provider is well liked, would have a skewing effect on patient satisfaction surveys.

Methods

Data collection for the frail elderly population was completed through in-depth, semi structured interviews with frail elderly consumer and their caregivers. Individual, one-on-one interviews were conducted at a setting of the participants choice. Most of these consumers were enrolled through either the PACE or Partnership programs at Eldercare of Dane County. Some interviews were conducted with well elderly for comparison data.

Additional data was collected using participant observation at the PACE and Partnership day center.

Data were collected and analyzed using the Grounded Theory research method. Accordingly, interviews were initially quite open and unstructured, allowing the subjects to establish the topics to be pursued. Subjects were encouraged to talk about health care experiences and how their condition and related services influenced other aspects of their lives. Following each new interview, an analysis was conducted and questions were altered accordingly. The consistency of topics identified by consumers led quickly to a narrowing of the interviewers' focus. Remaining interviews were used to elaborate on these areas, each time also confirming relevance of the topic.

RELATIONSHIP WITH PROVIDER

“And I told that to the doctor, and she was so sympathetic about it, that I couldn't believe my ears, that she was telling me such kind things and she was so sympathetic that it was just unreal..... And then when she left she had me come

into her office to talk to her, and the tears came to my eyes and I just cried and I told her she's the best doctor in the world." (CONS26A)

Relationships with providers were conceptualized as inextricably related to, indeed the essence of, the services. Quality of care could not be conceptualized apart from the relationship with the provider and the quality of those interactions. Medical outcomes, in most instances, were of secondary importance.

When asked specifically about outcomes, consumers would often describe an interaction with the provider to demonstrate the quality of the relationship rather than address clinical procedures or outcomes. When this consumer was asked to give an example of quality health care, she told the story of how her doctor had come by her home to check on her on Christmas day:

"Well I got sick over Christmas and I couldn't get out of bed...So Christmas day Dr. ____ come out to the house..she left some kind of number she has, that if she's someplace else I could call her, or my daughter could call her...Well, when she came to the house...I was pretty sick... She made you feel like you didn't put her out." (CONS05, 689-763)

In the context of a good relationship with the provider, elderly consumers described several examples of high quality care interactions. These examples demonstrated a high degree of familiarity, between patient and provider, and with provider behaviors that clearly reflected affection toward the patient. In this context, it was rare to find a negative comment about any aspect of the care.

Understanding the centrality of the relationship with the provider, and the implications of this on quality, was pursued throughout interviews with elderly consumers. Frailty can have a powerful, isolating effect. Many of the elderly consumers interviewed had few significant

relationships in their lives. Often they had few living relatives or friends near by. Consequently, having a history with someone (including health care providers) and continuity in a relationship was an important quality of life issue. For many of these frail elderly individuals, their health care provider had known and even cared for their spouses, siblings and friends who were no longer living. Thus, there was a real investment in maintaining relationships with health care providers who were connected to them in ways that went well beyond health care.

PROVIDER EXPERTISE

Expertise, from the elderly consumer's perspective, is the integration of clinical knowledge and intimate personal knowledge. Competent decisions can only be made if all that is unique and special about a particular patient is taken into account. This contrasts with clinicians' understanding of expertise as primarily related to knowing a clinical area which can be brought to bear on the treatment of a patient (someone they may or may not know well).

When expert care is defined as person-centered, rather than domain-centered, expertise can range from knowing how a particular person reacts to a certain drug to knowing the personalities of family members and how the consumer reacts to them. Consumers described high quality clinical decision making as always in the context of this 'personal knowledge', i.e. 'He would never ask me to do that. He knows how nervous it would make me.'

Therefore, a provider with whom the consumer has a good relationship, especially one of long standing, will always take into account the myriad of relevant, personal details before recommending treatment. This sort of provider would never suggest a treatment that the patient could not tolerate or would not have selected. Consequently, consumers who believed this felt very little need to understand all the possible side effects or even to choose among available

treatment options. Several consumers believed that since the provider knew them so well, the right decision would certainly be made on their behalf by the provider and their preferences would be realized through the provider.

Sharing Information

Providers were found to have a significant impact on a patients' willingness to disclose as well as how much, what, and in what way disclosing is done. A patient/provider relationship that is perceived by the patient as supportive, non-judgmental, and familiar creates the possibility for disclosing potentially disappointing or otherwise problematic information to the provider. Without such a relationship, important clinically relevant information is often withheld. Signs and symptoms experienced, as well as decisions about how to respond to them, are likely to be shared with providers only under the disclosure promoting conditions identified above.

The presence of evidence that disconfirms or the lack of evidence that confirms the existence of such a relationship results, frequently, in cautious or indirect disclosure, or nondisclosure. Significantly, one of the most difficult areas of disclosure is the lack of comfort with the provider. Cautious disclosure occurs when the consumer is testing the safety of disclosing and watching for a response. It generally involves giving responses that approximate what the provider wants to hear (as perceived by patient) yet opens the door for something else.

The provider's response is, in this instance, a powerful determinant of how the interaction proceeds and whether the elderly patient volunteers information that is contrary to what was hoped for. These offerings often come with qualifiers such as, 'Well, I think so..' or 'Probably' or 'I'm not really sure, but you're probably right.'

Silences were also used to avoid answering direct questions about following treatment instructions. These were especially common when the patient was unsure about the instructions or the questions being asked about symptoms. Silence and continued uncertainty over expectations was often seen as preferable to asking for clarification. Such a request could: reveal a deficiency in the patient, reveal the patient to be uncooperative, use up the providers time, or create more confusion.

When questioned about the possible consequences of continuing confusion and less than optimal treatment outcomes, elderly participants consistently insisted that their physicians were probably aware of what that patient was not revealing. There was a high level of faith in physicians ability to ‘read between the lines’, discerning what was not disclosed.

Other strategies used by elderly patients to reveal “unpleasant” information was to camouflage disclosure. This was especially true when making ‘veiled’ evaluative statements about the care. For example, it was common for frail elderly patients to comment that: “It must be difficult for you to work with someone so rude” or “My daughter was upset, but I’m not” or “It must be difficult to work in such a crowded place.”

PROVIDER COMPETENCE

The majority of elderly consumers suggested that competence included remembering details about the patients life and medical histories. In fact, very elderly, chronically ill consumers clearly relied on the ability of providers to retain the details about medical histories that the consumer was unable to retain. When providers begin interactions with elderly patients by asking questions or making comments that demonstrated the possession of this personal,

biographical knowledge, this provided confirmation and evidence of expertise that the patient would be treated competently.

On the other hand, when a provider revealed an absence of such knowledge, often by asking the consumer questions deemed inappropriate by the consumer, the consumer perceived this to mean that the provider was not only uncaring, but may not be competent to make decisions about their care. Being asked to provide details about medical or personal history suggested that the provider was relying on the consumer's memory and ability to understand the medical complexities in order to determine treatment plans. It also suggested that the relationship was not what the consumer believed it to be. This created fear and was quite disappointing to the consumer.

Consistently, consumers expressed that they did not have the knowledge or understanding required to provide detailed information about their condition. They often became frightened when they believed the provider was relying on their ability to recall (or understand) such details accurately. Specific examples of when this was done, included the following:

- A woman described being asked what her name was by a provider she felt she had a close, long standing relationship with.
- A woman described how the provider confused her with someone else and she wondered if she was getting the other persons medications.
- Several consumers expressing profound disappointment in providers who had forgotten about illnesses or injuries that had occurred in the past, or forgotten about a reaction that the consumer had had to a certain drug.

None of the consumers who discussed these issues believed that providers should have to review their charts in order to remember these details.

Interviews with this group of consumers suggests that if patients are forced to choose between a provider whose technical competence has been questioned but who has a good relationship with the patient, and a provider who has better diagnostic and treatment skills, but who is less connected to the patient, most elderly consumers will select the former. The importance of the interactions with providers and the meanings attributed to these interactions could result in the unquestioned acceptance of poor outcomes and care that is poor quality by professional standards.

EVALUATING PROVIDER COMPETENCE

There were a few instances in which retrospective assessments of the provider were altered by the acquisition of new information. A consumer who discovered later that a treatment, a medication, or a recommendation was not appropriate and may have even been harmful, reassessed the quality of both the care and the relationship. This reassessment involved a redefinition of the provider's commitment to or concern for the patient. Elderly consumers often interpreted inappropriate care as betrayal rather than evidence to reevaluate provider competence. A lack of competence was often explained by a new understanding of the relationship with the provider in which the provider did not 'really care' about the consumer.

There are several assumptions inherent in this reasoning: that physicians and other health care providers are aware of their limitations and know what they don't know, that providers have expertise in all areas and know how to obtain information they might need, and that providers know when a referral is appropriate. For elderly consumers interviewed, failure to do these things is more likely to demonstrate a lack of caring, than a lack of knowledge, skills or competence.

Referrals

None of the elderly consumers interviewed for this study criticized past or present providers for continuing to treat them rather than referring them to an expert. [Different than physically disabled population] In general, these elderly subjects believed that when providers did not have adequate expertise to handle the situation, they should continue to treat them while obtaining the needed information from appropriate sources. Referrals were explained as 'going beyond what is necessary' and 'double-checking' the initial opinion; making extra sure that this is the right thing to do. It was explained as evidence that the primary provider is "so concerned about me that he is being over cautious." It was an acknowledgment of a caring relationship with the consumer rather competent clinical decision making.

PROTECTING PROVIDERS' FEELINGS

The elderly group of consumers described an overall effort to be cooperative, and to do what the primary provider wanted them to do. Several consumers described 'going-along-with' decisions that they did not like or did not agree with. Most of these consumers did not consider it acceptable to ask questions, make suggestions, or openly disagree with the recommendations of their provider. A fear of upsetting others and the inability to come up with a 'reasonable' alternative were reasons given for 'going-along.'

Although a few were comfortable with open disagreement, most consumers would appear to agree, or, more often, just remain silent and then not follow the instructions. Rarely did any of these consumers reveal their intended lack of compliance to the provider. If the provider

discovered this it was generally because of feedback from family members or home health nurses.

Several consumers described instances in which they reported better outcomes (symptom relief) to providers than was actually the case because the patient did not want the provider to feel bad. This generally occurred when the patient felt that '(the provider) has done everything that could be done.' Providers were consequently 'protected' from failures and disappointing outcomes by elderly patients. It is easy to see how this can compromise the elderly patient's care.

When providers suggested to an elderly patient that a particular treatment would certainly be effective, patients described a reluctance to report failure and minimized problems or symptoms. Some consumers viewed this as protecting the doctor and some as hiding their own failure to respond 'correctly.' Not understanding that, in many instances, a variety of interventions must be tried before an effective one is discovered, patients often assumed that nothing more could be done unless they had been told there were other possibilities. Seeing a poor clinical response as a failure while assuming nothing else could be done, led to underreporting and minimizing of symptoms.

When a provider did let elderly consumers know that a 'failed or only partially affective treatment' was a possibility, and that it would not reflect badly on either the provider or the consumer, these consumers expressed a greater willingness to report.

Repeatedly, patients explained this as a strategy to spare the feelings of a provider who had done "everything possible." In some instances, patients described being uncomfortable giving such feedback since they were afraid they might be blamed, that the failure was somehow their fault. In other cases, the consumer translated the failed treatment as the providers lack of competence:

“..he gave me medication and said that it would work - and it didn't. I'm not going to tell him, though. I'm not going to tell him he's wrong or doesn't know what he's doing. My old physician, she was really good. She said 'This might work and it might not. This medication works for some people, but not for others. Medications are always an experiment.' ” (CONS040A, 9/96)

This was especially, but not exclusively, the case when directions had not been followed closely by the elderly consumer. This finding takes on even greater significance in the context of consumers' frequent reluctance to openly disagree with a proposed plan of care, even when they did not intend to follow through with it.

In these instances families were the ones most likely to insist that something needed to be done, and that the patient should not accept the outcome. Both families and patients interviewed for this study confirmed that families frequently played this role. In some cases, the consequence was that the family called, reported continuing problems, and made an appointment only to have the consumer appear in the clinic and deny that there were problems or that the problems were anything 'to worry about.'

CONSUMER GOALS

Consumers all have personal goals that may not be *obviously* related to the illness and treatment plan or to the decisions made about care. For example, wanting to fatigue less easily, to sit for longer periods of time, to walk more quickly, to hold urine longer, and to pull oneself out of a chair were all goals related to spending time comfortably with family and friends. These abilities all relate to not making people wait, not forcing others to alter their plans, and not relying on assistance from others. These goals were often experienced by these elderly patients as more important than the goals providers were working towards. Not taking account of these

goals, or seeing them as a lessor priority, often resulted in patients not following instructions.

Not attending to these patients priorities was clearly seen to undermine the effectiveness of the entire treatment plan. Social workers were found to be very skilled at discovering these goals.

Another condition found repeatedly to undermine the patients willingness to cooperate with treatment was the presence of an unpleasant symptom that the patient attributed to treatment effects. The symptoms most often identified were: dizziness, constipation, and urinary incontinence. Other symptoms which caused patients to abandon or alter treatment plans included: weakness, sleepiness, nausea and fecal incontinence. These latter symptoms were no less troublesome. They were simply described as less frequently occurring.

Descriptions of their responses to these symptoms suggest that while patients sometimes report these symptoms without being questioned about them, they are much more likely to report them if they were warned about them in advance, and told that something could be done about them.

Several elderly patients reported altering many aspects of the treatment plan, changing or eliminating all of their medications, in an effort to discover the causative factor. Common strategies were to take less of everything or to not take medications a few times a week. This altered treatment plan was rarely shared with providers. Patients were more likely to report that: 'Sometimes I forget' or 'I do it pretty much right.'

In addition to personal goals of consumers, most elderly patients interviewed referred to the presence of goals, regardless of their specifics, as important to maintaining a sense of hope and a future to look forward to. Having something to work toward, at least theoretically, was seen as very significant. Consequently, the absence or worse, the removal, of goals to work for was experienced as an abandonment of hope and an assault on their sense of personal worth.

"Not worth investing in" was the interpretation that frequently resulted from the removal of services that had previously been explained as important. Becoming physically stronger, regaining physical abilities, (physical therapy) regardless of how useful the abilities were, constituted monumental triumphs emotionally.

While providers may see treatment and therapy changes as part of the 'normal' course of events, elderly patients often attributed quite different meanings to ending a treatment, cutting down on therapy, or stopping a medication. The meaning of these changes was often related to the way in which the treatment was originally proposed. The termination of something that was recommended as a way to maintain functionality or health was often perceived as giving up. The difficulty here for the provider is to sort out when the patient perceives the change as 'giving up' on them and when the patient would prefer a less intense program. These are, of course, not mutually exclusive.

PATIENT CHOICE AND DECISIONMAKING

While wanting to appear cooperative, many frail, chronically ill, elderly consumers did express a desire that their wishes, goals, fears, intolerance's, sensitivities be central considerations in decisions made about their care. Many also expressed a desire to have their preferences acknowledged and implemented by others rather than being direct, active participants in the decision making. Consumers found comfort in the belief that their family members and their provider would make the right care decisions for them. This was especially true when the consumer did not understand the technical complexities or was too fatigued or too ill to participate in decision making.

Being able to accurately, sensitively, and comprehensively represent the consumers' view during decision making requires an intimate knowledge of both personal/biographical and medical details of the consumer's life. The inability to be actively involved, or the preference not to be involved, in important decisions increases the responsibility of other decision makers to present the consumers view. [Team issue] This is not equivalent to relying on a more generic or provider standards and assumptions. The providers' ability to do this is confounded by the frequent belief that standards of practice, safety concerns, or what the proxy decision maker considers sensible are acceptable substitutes for personal/biographical sensitivity.

Elderly consumers expressed the desire to be offered the opportunity to participate in a way that was not overly confusing, physically taxing, or personally intimidating. The desire not to anger, upset or disappoint providers and family members, the concern over 'getting someone (*specifically a well liked provider*) in trouble,' the confusion related to inadequate, or contradictory information, the physical, cognitive and emotional consequences of disease processes, and the often overwhelming amount and complexity of information were all identified as reasons not to be directly involved. These conditions were most likely to occur during times of stress, illness or sudden changes in condition. For these elderly subjects, an increase in illness/acuity resulted in less interest in being involved in decisionmaking. During these times they relied on family and caregivers to make appropriate decisions about their care.

There were several specific areas of decisionmaking that elderly subjects expressed a desire to be involved with. These included:

Choosing a Provider

The choice of care or service provider was important to all consumers

interviewed. Personal care workers and primary care providers were mentioned most often, and most emphatically, as important choices. Consumers generally were able to exert choice in primary care provider (PCP), sometimes contrary to the advice and wishes of family members.

Very few had experienced choice in personal care worker (PCW) despite the significance of this relationship. Elderly consumers were unlikely to believe that choosing a PCW was possible. They were more likely to take what (who) they were given and make the best of it, or decline the service altogether if that was possible.

Choosing a Clinic

Frail elderly consumers described several important considerations of clinic choice. These include:

- convenience of and comfort with location
- physical access
- staff familiarity with consumer (turnover in positions)
- adaptation of system to consumer peculiarities (without consumer request)
- provider knowledge/responsiveness to personal details
- having information available

While often unexpressed, these dimensions were consistently used by elderly consumers in evaluating the quality of the care they received and in determining their choice of clinic/provider.

The reluctance of many frail elderly patients to shift clinics and/or providers, even to follow-up on referrals, seemed often related, at least in part, to the significance of clinic staff. Even unpleasant clinic staff were sometimes preferred to someone new.

Elderly individuals talked repeatedly about the ‘wonderful’ care provided in places where staff made their familiarity with the patient quite obvious. This involved addressing the patient by name, making accommodations to preferences without reminders, i.e., “I know you always get cold, so I’ll put a heater in Room 2. You’ll have to wait a bit longer, but the room will be warm.” or “They seem to always lose your chart so I went over myself last night and told them to be sure the chart was here today.”

The areas these consumers identified as most significant were: comfort, availability of information, and acknowledgment of the relationship. Patients appreciated and were reassured by staff references to past events

Choice of Transportation

Choice of transportation to and from provider offices and home and the day center was spontaneously brought up by almost all the elderly consumers. In several instances, consumers described how long, jarring bus rides in the morning could exhaust them before they even arrived to receive services. It was also very important to these consumers that drivers be familiar to them and knowledgeable about them. One family member mentioned the fact that the van driver in the morning knew that his mother liked her lap covered during the ride. Another described how important it was that the driver knew how to lift his wife so she would not be hurt. Only those individuals who knew her were able to do this.

DECLINING SERVICE/PARTICIPATION

When services were declined, consumers often explained this to provider or others as a lack of need or ‘not feeling well today’ rather than expressing negative sentiments about the

provider or service. Often the consumer was unhappy with, fearful of, or confused by the service or provider but was reluctant to say so. Unwillingness to express negative sentiments was explained by:

- fear of retaliation
- fear of displeasing providers
- fear of being perceived as uncooperative or unappreciative
- fear of losing service altogether
- fear that the replacement will be worse

These fears were rarely spoken and required elaborate, indirect probing during the interviews to acquire this information. It would not be useful, in most instances, to ask for these assessments directly since the evaluations would not be forthcoming.

Consumer frequently described settling for services that they were unhappy with and, at times, declining the service altogether. This latter strategy was especially popular when a less desirable replacement was seen as no longer temporary.

There were some attempts made by elderly consumers and their family members to give feedback to staff and providers on a variety of topics. This was particularly true when consumers felt safe about doing so, with no fear of retaliation or disapproval. The feedback was still generally quite gentle and somewhat veiled.

One of the more common means of doing this was to 'just mention' something to the staff/provider the patient/family was most comfortable or familiar with. Frequently the person selected was a personal care worker, van driver, or day center staff. Comments were often camouflaged and delivered out of context so it would be difficult for the recipient of the message to appreciate the significance of a comment.

Many frail, elderly consumers also assume that these informal 'complaint/s' would be heard, understood, passed onto the appropriate person and formalized in a way that is not threatening. When questioned about this, consumers were all quite certain that 'mentioning' something in this way was tantamount to delivering the message to the provider who would most appreciate its significance. If there was no response to the 'mentioning', consumers assumed that a decision had been made to not respond because nothing could be done and/or it was not their (consumer's) place to comment.

The implications are clear for having clear, continuous communications among all staff and the importance of all staff being knowledgeable about symptoms.

POOR QUALITY CARE

There were several descriptions of "poor care" in which procedures went smoothly, outcomes were specifically what the provider was trying to accomplish, but the care was experienced as impersonal or insensitive. This situation was almost always defined by consumers as reflecting poor quality care.

When asked to comment on care that was clearly not done well by professional standards by a provider with whom the consumer had a good relationship, the response was often to minimize the technical problem and refocus the evaluation on the intent and concern of the provider. For example, elderly consumers responded with comments such as, "it (the care) was the best that could be expected," or "...it's no one's fault...those things happen even to the most experienced doctors..." or "(provider) tried so hard. No one could have tried harder."

Even when there was no prior relationship with the providers involved, care that was experienced as sensitive, supportive and friendly was almost always evaluated by the consumer as high quality care, regardless of the outcome:

“...I mean, they did the best they could. And they were concerned. They had that..an attitude that was concerned, you know, that made me feel better to know that they were taking good care of me.” (CONS09, 181-184)

Exceptions to this were generally explained as difficulties the provider was experiencing rather than the consumer. For example, a staff person's rude behavior or a technical problem with a procedure might be described as what created problems for the provider. One woman commented about a receptionist, "It's terrible (for provider) that he has to work with people like that. She (receptionist) makes it hard for him....gets people mad at him."

When faced with evidence that their care may not have been appropriate, elderly patients often reported feeling badly for the provider who must surely be suffering as much as the patient over the 'unfortunate mistake':

“I can't remember what he said but what he said made you think he was concerned about how I felt. It was the touch and the attitude that he was doing the best he could.” (CONS04, 173-175)

Discoveries about inappropriate care were generally either accidental or forced by concerned family members rather than the result of patients themselves raising questions about the care and initiating a search for an explanation. In these circumstances, patients usually continued to defend the provider explaining that "mistakes happen" and that the provider must feel as badly about it as they did. For these patients, such an experience rarely raised doubts about the competence of the provider or concern over the quality of future care.

The explanation for accepting less than optimal care is generally assumed patient ignorance of what could be expected and the psychological need to believe the provider. This is not, however, an adequate explanation of the “logic” observed. Even patients who understood the clinical details of their care focused on the affective dimensions. A closer examination of patient discussions revealed a logical and consistent explanation for this.

HIGH QUALITY CARE

Providers with whom elderly consumers had long histories and high quality interactions, were perceived as affectively motivated to provide high quality care. Consumers generally felt that such a provider, because of the established, caring, personal relationship, would always provide high quality care because the provider was affectively motivated to do so. Therefore, when a provider was affectively motivated, any failure to provide excellent care must be the consequence of factors beyond the control of that provider. A caring relationship was ipso facto both evidence and assurance of high quality care.

One consumer endured a very painful procedure for which she could have been safely and easily anesthetized. However, when she described the care, it was as the best care she had ever received. Her detailed description focused on how kind the physician and technician had been, how they had spoken with her throughout the procedure, making frequent eye contact while letting her know what was going on, and how they were sincerely disappointed at a negative outcome:

“The doctor stood by and the nurse was very, very helpful through the whole thing. She kinda talked me through it ‘cause it hurt so bad and was really, really good to me. And they were there too when I had to have my leg up with that sandbag on for eight hours at a time and it wasn’t their fault that the thing started

bleeding again...but they were very, very kind to me, both the nurses and the doctors. So I'd say that was one time that I had really good care." (CONS09A)

Other examples of high quality care were related to the motives attributed to providers behavior. In particular, taking time to stay with or visit with the patient, stopping by or calling "just to see how you are" (read) rather than because it is clinically indicated, checking up when it was not clinically necessary were all described as examples of excellent care. One consumer who had been extremely ill at home was visited by a physician who explained that "I just thought I'd stop by and say hello." The consumer took this quite literally as a socially, affectively motivated visit. This was her example of the 'best care' she had ever received.

Several other consumers made similar statements about visits from nurses and social workers. Each of these visits was planned as part of the follow- up care, although each provider had initiated the conversation with an exclamation of personal concern about the consumer.

Comments from consumers about the quality of care came repeatedly with descriptions about the quality of the provider-consumer relationship and what significance they believed the relationship had for the provider. Personal, biographical knowledge about the consumer, maintaining eye contact, using physical touch, and keeping confidences were used as consumer indicators of quality care. One of the important implications for the Partnership Program is the discovery of the magnitude and nature of significance of biographical expertise.